

## Group description

September 2024

### Design & Objective

In Kaart is an open cohort study that collects data from people (age 0-99 years) who are neurodivergent and/or have disabilities. In Kaart was set up by a multidisciplinary group of researchers ([www.inkaart.org](http://www.inkaart.org)) in close collaboration with stakeholder representatives, with the ambition to better describe and understand the social participation, social functioning, and wellbeing of people with neurodivergence and/or disabilities and their families, and contribute to their quality of life by investigating risk and resilience factors that may set them upon divergent developmental pathways. This is partly done by sharing findings with and through stakeholder interest groups. Strengths of In Kaart include the variation across type and degree of neurodivergence and disabilities and the participatory process of research agenda setting. In Kaart started to collect data from September 2022 onwards.

### Recruitment

Participants are recruited through convenience sampling. In Kaart is a partnership between researchers and stakeholder organizations, such as the parent organization 'Balans' and 'Impuls en Woortblind', in which each partner contributes to recruitment, based on shared agenda setting and dissemination.

### Procedure

Upon enrolling in In Kaart through the website of In Kaart, participants are required to complete an informed consent form online. After consent is provided, they receive a link to an initial baseline questionnaire via email. Participants are then invited to complete a follow-up questionnaire annually, which covers a range of additional topics.

### Personalized feedback

Two times a year, participants of In Kaart receive personalized feedback. In the fall of each year they receive a report about a selection of their answers compared to the group of In Kaart. On the condition of sufficient subgroup size, we additionally provide a comparison on sub group level. Furthermore, immediately after finishing the follow up questionnaire in spring, participant get a personalized report about their answers compared to their answers from the previous year.

### Privacy

Data such as names and email addresses are stored separately and off line. These data are only used by the data manager for administrative purposes. Researchers work with pseudonymized data only.

## Participants

In Kaart includes participants who have a (suspected) diagnose of Autism Spectrum Disorder (ASD), Attention Deficit and Hyperactivity Disorder (ADHD), developmental co-ordination disorder (DCD), dyslexia, Developmental Language Disorder (DLD), visual impairment and Intellectual disability. Parents can also report about their children (0-15 years old) without a (suspected) diagnosis if they are worried about their child's development.

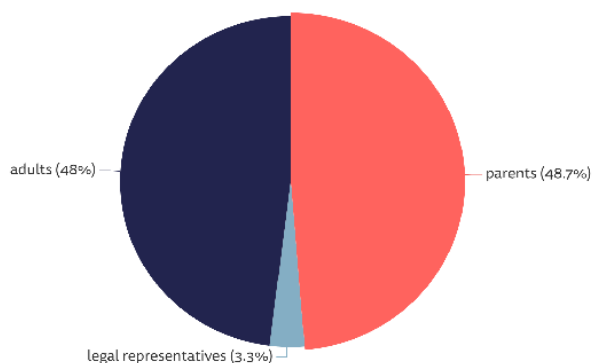
## Informants

In Kaart has three informants.

- Adults (16 years or older): they answer the questions about themselves (48%).
- Parents/guardians (younger than 16 years): they answer questions about their child (48.7%).
- Legal representatives: they complete the questions, where possible, together with the person they represent (3.3%).

**Figure 1**

*Informants of In Kaart*



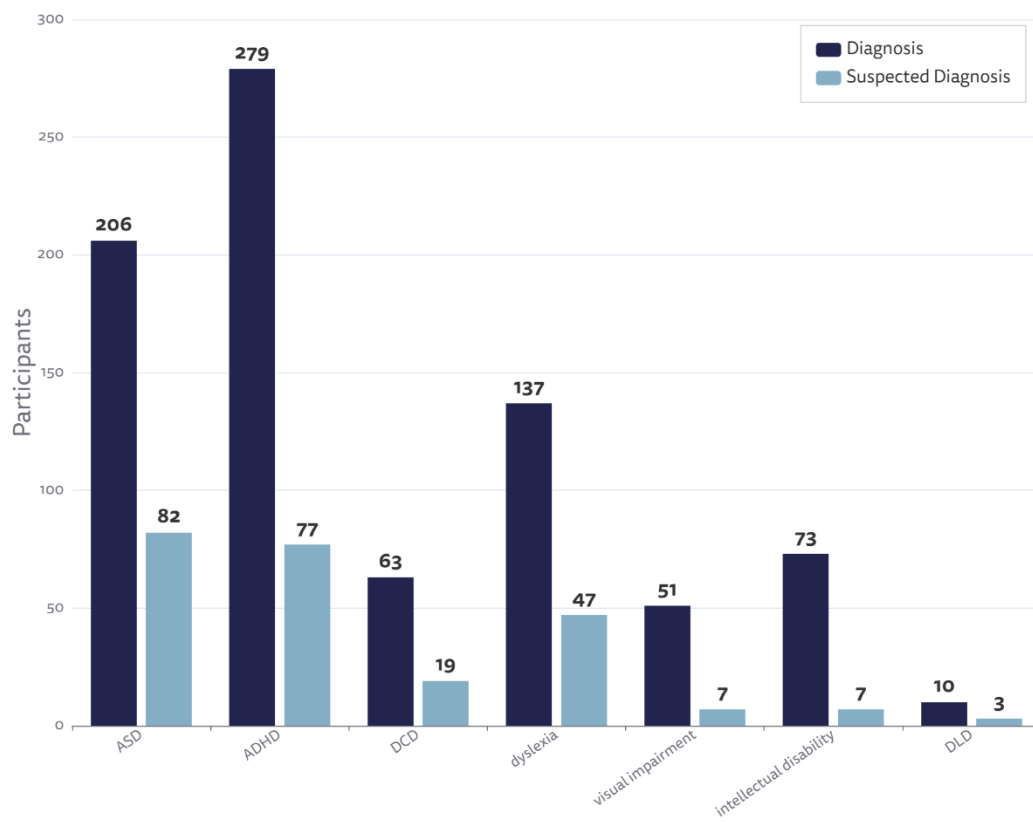
## Group Description

This section provides a description of the participants in the In Kaart study who enrolled between September 2022 and July 2024. During this period, a total of 870 participants registered. Among these participants, 93 are still in the process of completing their questionnaire. A total of 777 participants have fully completed the questionnaire or have been marked as complete after receiving three reminders. For our analysis, we focused on participants who completed 50% or more of the questionnaire, which accounts for 675 individuals. Of these, 14 participants indicated that they neither suspected a diagnosis nor were concerned about their child's development. Consequently, these 14 participants were excluded from our analysis. Therefore, the final group for this report comprises 661 participants.

## Diagnoses

In Kaart includes participants with different forms of neurodiversity and/or impairments. Most participants within In Kaart have a ASD and/or ADHD diagnose. We are committed to including more in the next coming years.

**Figure 2**  
*(Suspected) diagnoses*

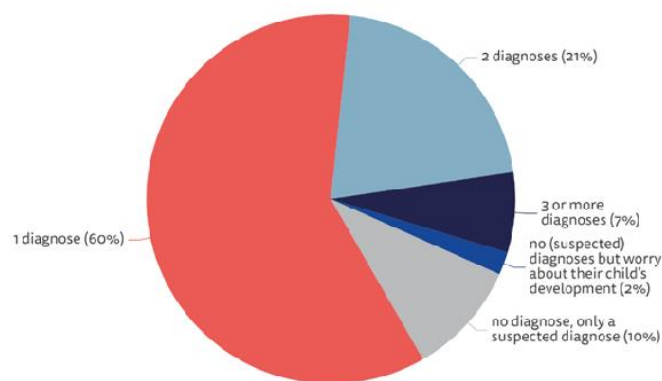


## Co-morbidity

60% of participants (all informants) of In Kaart indicate to have 1 diagnose. 28% of participants have two or more diagnoses. 10% have no diagnose but do suspect one or more diagnoses. 2 % does not have a (suspected) diagnose but worry about the development of their child. Total group N=661.

**Figure 3**

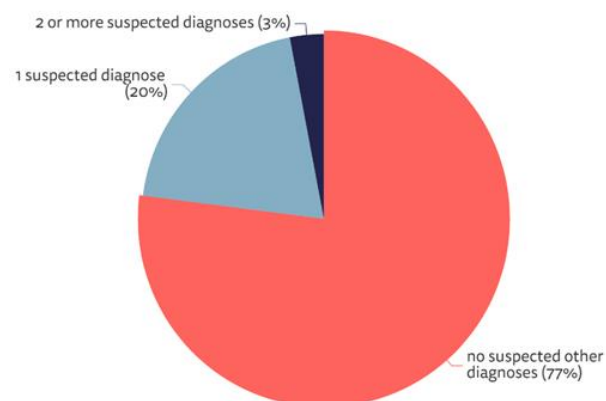
*Co-morbidity total sample*



77% of participants with a diagnose (1 or more) (N=582) do not have another suspected diagnose, but 23% of participants with a diagnose so suspect other diagnoses.

**Figure 4**

*Suspected diagnoses in participants with 1 or more diagnoses*



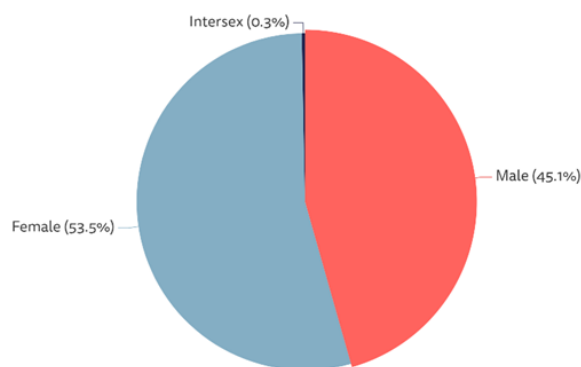
## Sex en gender

### *Sex assigned at birth*

In Kaart consists of slightly more females (53,5%) than male (45,1%). Intersex made up of 0,3% of the total group (N=660).

### **Figure 5**

#### *Sex assigned at birth*



### *Gender identity*

44,5 % of the total group (N=661) identified as male, 51,1% as female. 3,3 % identified as non-binary or other. 1,1 % did not know or did not want to share.

## Age

In Kaart includes participant from 0-99 years of age. The mean age of the current participant is 26,1 years old. The youngest participant is 1 years old and the oldest participant is 78 years old.

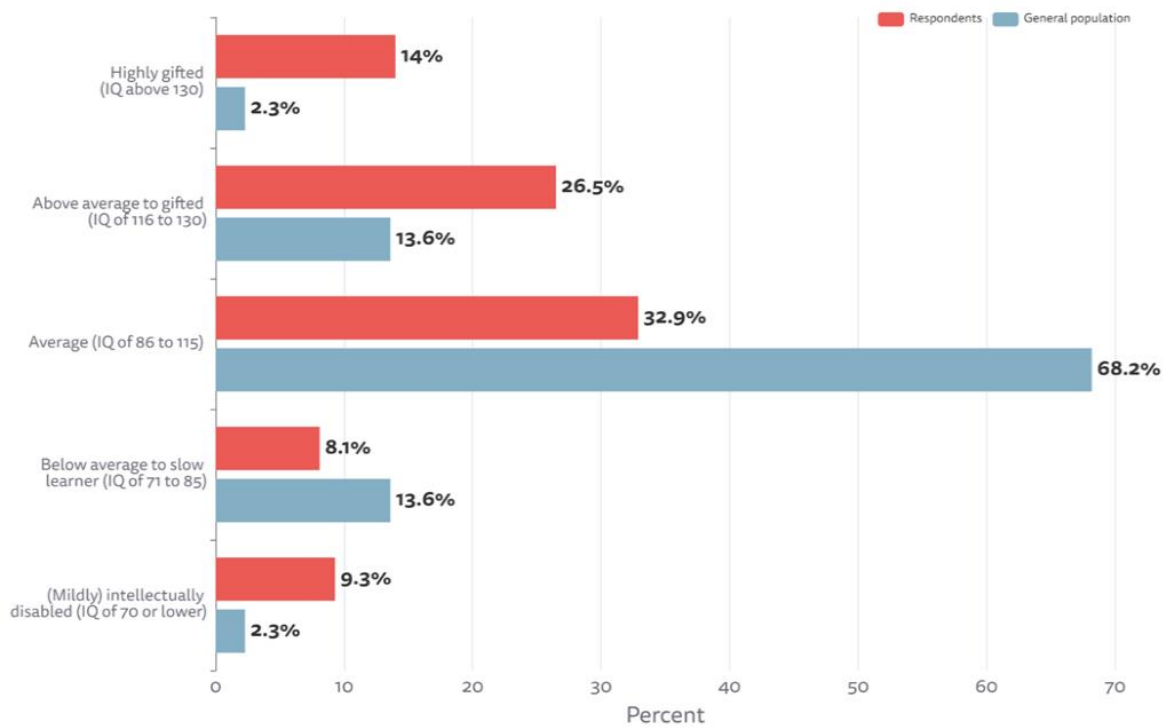


## IQ

IQ within In Kaart is distributed differently than in the general population. Within In Kaart there are more people with both high and low IQ levels.

**Figure 6**

*IQ*



Note: total sample N=422

## Working with the data

Researchers can use pseudonymized In Kaart data for their research if the steering group of In Kaart approves a research proposal (). We strive to review the request within 2 weeks after which the applicant will be informed of the decision. If the request is not approved, you might be requested to revise the proposal and resubmit. Once your data request is approved, researchers are asked to sign a data sharing agreement (DSA). Once we receive a signed data sharing agreement, data management will prepare a dataset. A typical data request takes approximately 2 weeks to prepare, but this depends on the complexity of the dataset and the availability of the In Kaart team. Please contact us through [inkaart@vu.nl](mailto:inkaart@vu.nl) if you have any comments or questions.

## Data common core

Here we describe the content of the baseline questionnaire (common core). For more detailed information please contact the In Kaart team: [inkaart@vu.nl](mailto:inkaart@vu.nl)

### Sections:

- *Personal Information*: Relationship to child/individual represented, marital status, gender, IQ
- *Education*: Current education, special education types, highest level of education completed, satisfaction with education
- *Family*: Ethnicity, information about biological and caregiving parents, parents' employment status
- *Developmental Challenges*: Diagnoses/suspected issues, background of concerns, \*background of worries about the child's development, received assistance, satisfaction with assistance, \*limitations in daily life due to the developmental issue (IRS<sup>1</sup>), \*pro-social behavior, emotional problems, behavioral problems, hyperactivity, and peer problems (SDQ<sup>2</sup>), (suspected) diagnoses in family members, other diagnoses
- *What is Going Well*: Open questions regarding support, learned skills, and strategies for handling difficult moments
- *\*Diagnosis Information*: Age at diagnosis, location and by whom the diagnosis was made
- *\*Benefits of Diagnosis*: Experienced benefits, positive aspects of the disorder
- *\*Treatment and Support*: Received treatments, medication usage, guidance, satisfaction with treatment, medication, and support
- *Physical Health*: Height and weight, complaints and illnesses, health satisfaction, motor skills
- *Living Situation*: Living conditions, type of accommodation, satisfaction with living situation
- *Happiness and Relationships*: Quality of life (EQ5D<sup>3,4</sup>), satisfaction with relational status, \*\*/\*\*\*\*emotional and social loneliness (Loneliness Scale<sup>5</sup>), quality of life (Cantril Ladder<sup>6</sup>)
- *Daily Activities/Work*: Employment/daily activities status, type of activity, satisfaction with work/daily activities, \*\*sources of income
- *Advocacy*: Membership in a patient organization or association
- *Tips for Others in Similar Situations* (see: [Tips van deelnemers | In Kaart - register voor en door mensen met ontwikkelingsproblemen.](#))

Specific Questionnaires within the Common Core: Participants who indicate having a diagnosis of X will automatically receive the specific X questionnaire. Additionally, participants can choose to fill out specific lists, if applicable.

#### *Autism:*

- Autism Screening (AQ<sup>7</sup>)

#### *DCD (Developmental Coordination Disorder):*

- Motor Functioning (\*Little DCDQ 8<sup>8,9</sup>, \*CVO<sup>10,11</sup>, \*\*ADC<sup>12</sup>), motor examination and outcome, concerns about motor skills (when and where first expressed), first noticeable abnormal motor behavior, problems with motor activities at home and/or school, impact of motor problems on academic performance and social functioning.
- Treatment and Support (when first sought help, received treatments/care or support)
- Sports Participation/Physical Activity (membership, type of sport, frequency, physical activity norms)

#### *Visual Impairments:*

- Visual Function Examination (period/location of eye test, visual acuity, visual field, contrast sensitivity)
- Eye Condition (type of condition, heredity, progression)
- Screening (self-reported vision, Weiner scale – severity<sup>13</sup>)
- Impact (IVI-28<sup>14</sup>)
- Specific Care and Support (type of organization, duration)
- Additional Questions (glasses/contact lenses, use of a cane/guide dog, special education)

#### *ADHD:*

- Attention Problems, Hyperactive and Impulsive Behavior (\*SWAN<sup>15</sup> and \*\*ADHD-RS<sup>16</sup>)

#### *Dyslexia:*

- Reading Skills (READ questionnaire<sup>17</sup>)
- Impact of Reading Problems (academic and emotional impact<sup>18</sup>)
- Support (support for individuals with dyslexia by school, parents, teachers, peers)
- Perceived Effects of Treatment

#### *Intellectual Disabilities:*

- Personal Factors (\*daily activities, type of care or support, role as a representative (MDS VB<sup>19</sup>)
- Self-Determination (subscale of self-determination from the POS-A<sup>20</sup>)
- Adaptive Functioning (communication, daily living skills, and social skills/relationships (Vineland3 short form<sup>21</sup>)

#### *Developmental Language Disorder:*

- Support (support for individuals with dyslexia by school, parents, teachers, peers)
- Perceived Effects of Treatment
- Language skills/type of language problem
- Intelligibility in Context Scale (ICS)\*
- Communication in daily life
- Consequences of TOS

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\*Only for participants under 16

\*\*Only for participants aged 16 and older

\*\*\*Only for participants who have reported having a diagnosis

\*\*\*\*Only for legal representatives



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